

I am Rachel Lidov, parent of a former high school student exposed to the WTC disaster. In 2001, I was a member of the Stuyvesant High School Parents Association Political Action Committee which later became Concerned Stuy. In 2002, I co-founded 9/11 Environmental Action. Both organizations worked with many groups to press for a science-based indoor cleanup. We then fought for healthcare and compensation for those affected.

Often I speak for others, today I speak also on my own behalf as a parent.

As a resident a few miles north, in Manhattan's Morningside Heights, it was shocking to breathe the air wafting uptown. It was more shocking to attend early community meetings and to learn what the residents and workers, and the students from other parts of the city were being subjected to. It only took a month or two for me to figure out we needed immediate action to create a registry of all those who were affected. It took us years to get any level of government to even consider our unified demand for it.

While as a citizen, I continue to be appalled that we cannot do better to protect today's children from emotional and physical harm caused by violence *and* natural disasters, I am not surprised.

And so I wish to emphasize today my support to establish a full cohort of younger people affected by the "WTC disaster" that we have sought for the last two decades. Let me point out just two issues.

We need to have people who can do this in real time - to make personal contact with those who have been left out.

In September 2001, many of the "young people" were verging on entering adulthood. Some already were young adults. These people are now newly of middle age or will be middle-aged in a few years. At the time of attack on the WTC, the downtown community, the city, indeed the country, was in shock and the many government agencies who should have been protecting the pregnant women, babies, children and teens, and very young adults were busy telling everyone there was nothing wrong with the outside air or the dust that was blown into the many buildings.

And some were within months of being born.

When the CDC and the NYC DOHMH finally established a registry many of these people had already scattered or were too young to realize their need. Many are in NYC but many are all over the country. They are in other countries. Sending letters to family addresses from 2001 or 2002 won't do the job.

Yesterday, the STAC and the Program heard from the people exposed as children who are now adults and who are advocating for the Program to include them in research so that their needs

might be met in the future. This is what we have fought for over 20 years. NIOSH/WTCHP must address the knowledge gaps now. The first step is committing to this new cohort.

We need longitudinal studies of the larger population.

Need I point out the toll that a decade of coverup of the dangers in the smoke and dust deprived us of the opportunity to begin clinical studies. And yet, some dedicated community organizations and individuals like Dr. Reibman did begin the work through local hospitals. While the community supported these efforts, if they knew of them, we have never been fully successful in getting long-term commitment from the city or the federal government to fund them.

There have been some attempts to survey the population but again, will the effort now on the table be fully supported by NIOSH so that this can be done more methodically? Epidemiologists have established scientifically sound methods for comparative studies of similar populations in urban areas, which can be applied to the impacts of the destruction that occurred in the area immediately around the Twin Towers, to say nothing of the continuing upheaval in the surrounding environment that came with rebuilding across Lower Manhattan.

Such studies could guide science and medicine to an understanding of the impact of environmental exposure, how to treat those affected and why such exposures should be reduced and prevented in the future by agencies whose mission is to protect human health and the environment. We owe it to the children in harm's way on 9/11, and in the months thereafter to get answers that could help them now. These answers *would* help the *entire* 9/11 community, especially women who are a minority of the responder research cohort

This work will take a long-term commitment from NIOSH/WTCHP. It is incumbent upon you and the Program, to join with us, to demonstrate the will to build and maintain the cohort that the young survivors themselves are calling for.

Thank you for this opportunity to speak to you today.